

Prior to his final hospitalization and death, my brother Curtis was a 62 year old man with a functional age of 11-15 months. Curtis, residing in a Residential Habilitation Home in the community, was very happy and extremely active, sometimes sleeping only 3-6 hours a day. With the assistance of a Merry Walker he ambulated freely through his house and was taken for frequent walks outdoors. When Curtis was diagnosed with pneumonia every effort was made to keep him in his familiar surrounding where he could maintain his routines and be free of the confines and restraints that hospitalization would require. Lack of understanding and therefore compliance with treatment led to the necessity for a visit to the Emergency Room.

The day of the ER visit, the MD notified us of the seriousness of Curtis's condition. Curtis was diagnosed with Acute Respiratory Distress Syndrome. We as guardians (my parents and I served as co-guardians of Curtis) elected to have Curtis placed on comfort care. Soon we were notified that this was not an option due to a statute to protect the developmentally delayed in the State of Idaho. We were not only legal guardians, we were family members. We had more than a legal interest in our Curtis. We were now forced by a statute to let the medical professionals perform undesired medical interventions that we would never choose in our advanced directives for our own care under similar circumstances. Curtis was intubated and became a patient in ICU.

The Ethics committee at St. Luke's Hospital was approached the next morning. The statute prohibited any action on their part other than continued intubation. I was assured that this was the "thing that had to be done....statutorily"

Some days later extubation was attempted and less than 24 hours later he had to be re-intubated. During this time, I was present and Curtis many times indicated with his limited sign language that this was not acceptable. Oxygen mask and partial sedation with restraints was not part of his active lifestyle.

This statue which was intended to give him rights was actually taking away his rights to refuse life saving measures that would only serve to prolong his dying process. There were many efforts by the medical team to change the care plan.

Doctors kept saying treatment was futile. The statute kept them from honoring wishes on his behalf.

Finally, after 21 days of torturing Curtis with futile treatment, we met with the Guardianship Judge and were able to get amended orders of Guardianship and have Curtis removed from all life support. Curtis died approximately 48 hours later. Curtis spent his last two days with family and was allowed to die with dignity even though the legal restrictions and circumstances did not provide him the opportunity for him to die at home.

My heart ached and tears ran down my cheeks as I watched him lay lifeless in his bed with a machine taking every breath for him. It seemed so wrong that he was not up and running.

Grief was multiplied for me. I actually had to go through the legal system, feel at times that I was a criminal (going through security, be sworn in,...etc.) and plead for a judge to make a decision about someone that he had never seen, could not really care about ...and hope that he would make the decision that would keep my brother from living out his life in a ventilator/trach unit. These legal issues were an unfortunate distraction that robbed me of my time in these last, precious few days with Curtis.

I loved Curtis. The love I had for Curtis was somehow different than that I have for other people in my life. I can't explain... it is just different. He was my "big brother", but developmental challenges kept Curtis from being the "big bro" that protected me from all the bad things and wrong boys a little sister might be exposed to. But he taught me so much without ever uttering a word.

For many years society did not accept Curtis, and others like him. Families were encouraged, sometimes mandated, to institutionalize those that were developmentally disabled. How that makes my heart ache.

From Curtis, I learned to nurture, care for and accept imperfections in people. I have learned from Curtis that life can be simple. His frustrations, anxiety and suffering were always been escalated due to rules and regulations. Curtis was happy drinking coke or coffee without a shirt and helmet. Curtis was happy

playing a quick game of tug of war with a bandana. A great pleasure in his life was taking a brisk walk out of doors. He loved and rewarded his favorite caregivers with a hug and a smile.

Many times I have met people that have worked with Curtis. They all loved and adored him.

In the end, I had to meet with a Judge and ask that Curtis be free of the machines that bound him. I am a nurse that has endured many difficult circumstances and helped countless families through the death and dying process. Despite all that, this was the hardest thing that I have ever done. I loved Curtis and his life. All I wanted was the right thing for him.

I am grateful for Curtis and all that he taught me. Because of him, I am the nurse that I am today. For many years I have asked why he had to endure all of his challenges. Perhaps I know now. I come before you now to ask that you help me to honor his life and his sacrifices. They stand as a reminder that we can do better and that we should. This bill will serve as a legacy of Curtis' life, example and sacrifices.

Ginger Wardhaugh

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